What have we been learning: From Person Centered Planning to Person Centered Thinking to A Person Centered System

Support Development Associates
September 2011
We want a system where -

• The people who use the services (with the support of their families)
  – Tell us how they want to live
  – Make use of the public resources to have the life they want (or as close as we can determine)
  – Get the support they need to make the first 2 happen
But, while demand is increasing in all states funding is decreasing (in many states)

• Unless we change how we think and act - funding cuts result in -
  – Increasing the number of people living together
  – Increasing the size of groups in day services
  – Increasing the time spent in groups
When we look at the next decade

• There is no sign of increased federal funding;
• Demand for services will continue to rise;
• Costs of current services are too high to increase them to meet demand; and
• Our the labor force (women 24 to 44) will not increase but demand from us and aging will increase
Demographics: The Adult Population is Aging

Demographic Shift = America’s Care Gap

Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005

Larson, Edelstein, 2006
Medicare and Medicaid Expected to Rise Rapidly, Other Programs (Except Social Security) to Shrink

Spending and Revenues as a Share of GDP

Federal Revenues

Source: CBPP projections based on CBO data.

Center on Budget and Policy Priorities | cbpp.org
Just when you thought it was bleak enough...

• As we learn, we don’t stop doing the old, we just add the new

• The response to abuse and misuse is rules to prevent them

• The result is layers of programs and layers of rules

Neither helps with effectiveness or efficiency
What needs to change?

**Nearly everything**

- How we think about services,
- How we organize services, and
- How we deliver services
Leadership’s challenge

• Create
  – a shared vision – a clear sense of direction and goals
  – A sense of urgency – change starts now

• Enlist those who share the vision as allies and partners –
  – Families, self-advocates, providers –
    • Need the skills and support to “pull” and “push” the system in the direction of the vision and
    • Spread success stories and defend the vision

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Leadership’s challenge (2)

• Align all the pieces of the system to support the vision
  – Have the “incentives” in the system support the desired outcomes – e.g. employment

• Offer the “legacy” parts of the system the assistance needed to change
Every state has 5 stories

• The best practice delusion
• Stories inspire but stories can mislead
Sequential Shared Delusional Disorder

• A shared belief that there is a single, simple answer to a complex problem which when reality demonstrates is not sufficient is followed by -

• Moving to another single, simple answer which is also a partial answer followed by –

• Moving to another single, simple answer which is also a partial answer followed by -

• And so on
The Evolution of Some of the Efforts

- Training in Person Centered Planning
  - 1990’s
- Training in Person Centered Thinking
  - 2001
- Training + the Development and Support of Coaches
  - 2002
- Training and Coaches + the Sustained Engagement of Organizational Leadership
  - 2005
- Training, Coaches, Organizational Leadership + Sustained Engagement of System Leadership
  - 2006
IF YOU WANT TO CHANGE VALUES, START WITH BEHAVIOR

BURKE
Inspection to improve quality is too late, too ineffective, and too costly…

Quality cannot be inspected in…

Quality must be designed in

Deming
Discontent is the engine of change

• Good plans create a kind of mirror – they reflect how people want to live
• Discontent comes from comparing what is with what could be

• There are 2 kinds of discontent –
  – **Optimistic**, and
  – Cynical
Moving from Service Life to Community Life

- **Service Life**
  - Important for addressed
  - No organized effort to address important to

- **A Good Paid Life**
  - ‘Important to’ recognized
  - ‘Important to’ present
  - Focus on connecting, building relationships and natural supports

- **Community Life**
  - To and for present
  - Closest people are paid or family
  - Few real connections
  - To and for present
  - Active circle of support
  - Included in community life
Moving from Service Life to Community Life

Service Life

- Important for addressed
- No organized effort to address important to

A Good Paid Life

- To and for present
- Closest people are paid or family
- Few real connections

Community Life

- To and for present
- Active circle of support
- Included in community life
The importance of the environment

Power Over

Toxic
Tolerated
Supportive
Healing

Growth occurs here

Power With

Support Development Associates, LLC
Helping people move and stay in the community

• It begins with learning how each person wants to live
Colleen

**Colleen’s introduction:**
The “mayor” of her neighborhood, volunteer of the year
Always helping others, humans and cats in need

**Important To**
- Feeling respected
- Having control
- Being helpful

**Important For**
- To never physically hurt others again
- Staying safe while living in the city by herself

**Instructions for Supporters**
Always ask – never order
Keep a good relationship with neighbors so that they will call when there is something amiss
Come by often enough to know when
  - She has a new “roommate”
  - More cats then space
Help the extra people move on; the cats find a new home
Helping people move and stay in the community

• It continues with learning what a good or better life would look like
Tammy's Description

Tammy's One Page Description

What People Like and Admire about Tammy (Pg 6)
- Is always smiling
- Totally accepts people
- WONDERFUL personality
- Stylish
- Accepting and forgiving
- Resilient
- Great sense of humor
- Friendly and social

What is Important to Tammy (Pg. 7-8)
- Being a part of things
- Having eye contact with everyone
- Looking stylish and having her hair and nails done
- Being comfortable and not having her tubes underneath her
- No roughness in personal care

Supports Tammy Needs to be Happy, Healthy and Safe (Pg. 10-14)
- Always have her head elevated
- To be suctioned frequently (5-6 times per shift). Gurgling noises means she needs to be suctioned
- To have people be kind, sensitive, loving and have a gentle touch
- Be gentle with brushing her hair (she doesn't like it, but wants it to always look nice)
- Always make sure her clothes match and make sure it's not sweat clothes
- Tammy needs to be repositioned every two hours
- Always follow through with a promise or give an explanation of what is going on and when you can keep the promise if something comes up
- Be sure to have Tammy use her body to keep flexible

Tammy's Picture Of A Life (Pg. 19-21)
- Live in a big wheelchair accessible home with extra wide doors, close to her family
- Have a fun and social housemate
- Have a beautician she can go to regularly
- Have a social medical day program close to home
- Have specialized medical services and medical equipment (including backup generator)
Tammy’s Description

A Picture Of A Life For Tammy

What would the ideal place to live be like for Tammy? What would it look like? What supports would be needed? What would he be doing during his day? Based on this ideal, what realities can be provided? How would they be funded?

Tammy Would Live...

- In a big spacious home that is wheelchair accessible and has extra wide doors
- With 24 hour awake staff that are kind, caring, and well trained
- Where her medical needs can be monitored closely
- With a housemate who is fun and social
- Where there is a covered patio so she can sit outside
- In a home with a lay down tub
- Where there is a connected garage
- In a home that is a single level
- Where there are quadruple outlets available for her medical equipment
- Where there is a wheelchair van available
- No more than 35-40 miles away from family
The Basic Approach:

Person Centered Thinking leads to

Person Centered Practices which lead to

Person Centered Organizations which create

Person Centered Systems that support Person Directed Lives
The structure of the effort -

- Teaching person centered thinking skills
- Developing and supporting coaches to spread the skills
- Creating structured ways for leadership to listen to coaches
- Building local capacity/creating sustainability
  - Person centered thinking trainers
  - Teaching leadership/quality management skills
- Intentionally building better partnerships between all of the key stakeholders
Responsibility:
Identify those things that are important to people who receive support; implement strategies to assure they are present in day to day life. Identify areas where change can happen without further approval or permission. Act on those areas.

Development:
- Person Centered Thinking Training two days for every staff member.
- Coaches training one day
- Coaches support meetings every other month.

Key Players:
- Coaches
- Direct Support Staff
LEVEL 2
Person-Centered Organization

Responsibility:
Alter and implement changes to policy, practice, structure, rules, organizational culture, business processes, standards or requirements as needed to create a person-centered organization.

Development:
• Initial Leadership participation in Person Centered Thinking Training
• Identification of Success and Outcomes for People Supported, Employees and the Organization based on Vision of Success
• Leadership meetings bi-monthly Supported by SDA
• Shared learning & implementation strategies across locations

Key Players:
Community Agency Directors
Executive Management Staff

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LEVEL 3
Person-Centered System

Responsibility:
Collaborate with state agencies to make the necessary changes in policy, practice, infrastructure, business processes and rules which impact the presence of person centered practices. Identify and re-design system-wide practices which maintain a medical/functional improvement approach so that the resulting system is based on person-centered practices.

Development:
• Initial Training in Person Centered Thinking
• Participation in all Leadership Team Support Meetings to identify Level Three changes needed and develop action plans for change.
• Training on quality tools to implement improvement efforts.

Key Players:
State Office Exec. Management Staff
What is Person Centered Thinking?

- Structured methods for people who are paid to provide support to think about quality of life from the perspective of the person they support
- A way to have teams pay attention to the balance between “important to and important for” with each person they support
- Tools that help with problem solving by focusing on the right questions
- It is a person-driven approach to services, rather than an agency-driven approach.
Introduce and apply person centered thinking skills

• Formal training for –
  – All managers – senior, middle, front line
  – Selected direct support staff
  – Key players, the “opinion molders” among the
    • self-advocates, family members, board members, funders, inspectors, service coordinators, etc.
Skills for Learning/Tools for Implementing

- Reputation
- Matching Staff
- Communication chart
- 4 + 1 ?s
- Learning Logs
- Good Day/Bad Day
- Donut
- Working/Not Working
- Rituals

Important to/Important for
THE CORE CONCEPT: IMPORTANT TO AND IMPORTANT FOR
SORTING IMPORTANT TO/FOR

○ IMPORTANT TO?

○ WHAT ELSE DO WE NEED TO LEARN/KNOW?

○ IMPORTANT FOR?

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Important TO:

What is important to a person includes those things in life which help us to be satisfied, content, comforted and happy. It includes:

- People to be with /relationships
- Things to do
- Places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have
Important To

• Includes what matters the most to the person – their own definition of quality of life.

• What is important to a person includes only what people “say”:
  - with their words
  - with their behavior

• When words and behavior are in conflict, listen to the behavior.
Important for

What is important for people, includes only those things that we need to keep in mind regarding–

• Issues of health or safety
  • Physical health and safety, including wellness and prevention
  • Emotional health and safety, including support needed
• What others see as important to help the person be a valued member of their community
All Choice
No Responsibility
Balance
Safety
Hear

Important TO

Important FOR
Balancing Important TO and FOR

• Sequence matters: learning about what matters the most to the person first, is a critical aspect

• It is not about either/or; paying attention to health, safety and valued social roles is critical, but alone it is insufficient if not in the context of important TO.

• Risk management techniques currently often focus on assuring safety or health at the cost of what creates satisfaction for the person; need to change our frame of reference to believe that both can co-exist
Ask Yourself “What do we know?”
Before asking “What do we do?”

If I had an hour to save the world, I’d spend 55 minutes defining the problem.

~ Albert Einstein
Important To/Important For

For the Person
• Helps people get more of what is important to them without ignoring important for
• Identifying what still needs to be learned
• Helps people make critical decisions only when the relevant information is present

For the Organization
• Teaches critical thinking
• Reinforces “think before you act”
• Helps people feel listened to
• Supports an active learning culture

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Discovery/listening tools

• Good day/bad day
• Rituals and routines
• Reputation
• Communication chart
• Relationship map
• 2 minute drill
Good Day/Bad Day

- What is a good day like for this person
- What is a bad day like for this person
Good Day/Bad Day

For the Person -
• Tells us what is important to the person
  – What needs to be present
  – What needs to be absent
• Gives good information on how to support
• Tells us who a good match is

For the Organization –
• When a number of these are put together:
  – Shows what is being done well and should be maintained
  – Describes what is not working and should be changed
Rituals and Routines

The importance of day to day routines and special occasions –

• Morning rituals
• Going to bed rituals
• Transition
• Holiday/Birthday
• Spiritual

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Ed and a cup of coffee
Rituals and Routines

For the Person –
• Others know what is important to the person in day to day life
• Rituals are more likely to be honored

For the Organization –
• Increases satisfaction among those who use their services
• Decreases challenging behavior
Listening to behavior...
A communication chart

<table>
<thead>
<tr>
<th>What is happening</th>
<th>__________ does</th>
<th>We think it means</th>
<th>And we should</th>
</tr>
</thead>
</table>

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Rhonda –
• Loving
• Adaptable
• A good trainer
• Patient and tolerant
• A good listener
• Knows what she wants
• Outspoken
<table>
<thead>
<tr>
<th>What is Happening</th>
<th>Rhonda does</th>
<th>We Think It Means</th>
<th>And We Should</th>
</tr>
</thead>
<tbody>
<tr>
<td>You are pushing Rhonda</td>
<td>Locks her chair</td>
<td>I don’t want to go there</td>
<td>Figure out with Rhonda where she wants to go</td>
</tr>
<tr>
<td>Rhonda is at the front door</td>
<td>Kicks the door</td>
<td>I want to go out</td>
<td>Help her outside (unless there is too much pollen, about to rain, etc.)</td>
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<tr>
<td>Rhonda has stopped eating</td>
<td>Catches your eye, pulls down napkin</td>
<td>I’m done eating</td>
<td>Take leftovers away now</td>
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<tr>
<td>You didn’t remove her food</td>
<td>Rhonda sweeps the food off her tray</td>
<td>I told you I was finished and you didn’t listen</td>
<td>Clean up and do better next time</td>
</tr>
</tbody>
</table>
Communication Chart

For the Person -

- Use of the communication chart in day to day support insures that -
  - There is an increase in the presence of what is important to the person
  - People using services feel listened to
- There is a decrease in frustration and the behaviors that go with it

For the Organization -

- Recognizes learning done by those who support
- Reinforces learning culture
- Provides new/relief staff with a quick way to get off to a good start
- Decrease in challenging behaviors and therefore a decrease in incidents
- Increases/reinforces observational skills

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Management tools

• Matching staff
• Communication chart
• Donut
## Matching

For each Person – what are . . .

<table>
<thead>
<tr>
<th>Supports wanted and needed</th>
<th>Skills needed</th>
<th>Personality Characteristics Needed</th>
<th>Shared common interests (would be nice to have)</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>
Matching staff with those who use services

For the Person -
• Because staff find more pleasure in their work they stay longer (more stability)
• Where there is a good match –
  – People who use services are more likely to have what is important to them
  – New learning about what is important to people is more likely to happen

For the Organization -
• Reduces turnover
• Makes those who use and provide services feel valued/respected
• Helps support “real” relationships
• Decreases likelihood of incidents
THE DOUGHNUT

USE JUDGEMENT & CREATIVITY

CORE RESPONSIBILITY

NOT OUR RESPONSIBILITY

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Defining Roles and Responsibilities – using the “Donut”

For the Person -
• Makes it more likely that those things that are most important (to or for) will happen
• People will be creative in support
• Those paid will “keep their noses out of” those things that are not their paid responsibility

For the Organization -
• Builds a culture of accountability
• Clearly delineates who is responsible for what
• Supports being creative without fear

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Tammy’s Description

Tammy’s One Page Description

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Mindful Learning Tools

• Working/not working
• Learning Log
• 4 + 1 questions
<table>
<thead>
<tr>
<th>From Julie's perspective</th>
<th>What makes sense? What works? What needs to be maintained? (The Upside Right Now)</th>
<th>From staff perspective</th>
<th>What doesn't make sense?... What needs to change? What doesn't work? (The Downside Right Now)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Shopping as often as possible, daily even, for favorite things</td>
<td></td>
<td>Staff don't let me drink whatever I want</td>
</tr>
<tr>
<td></td>
<td>Having lots of jewelry and watches to choose from and no one getting into them until I tell them it's OK</td>
<td></td>
<td>The dog has to go in the other room during mealtime</td>
</tr>
<tr>
<td></td>
<td>Having my sister, Joanne, who lives in Seattle in my life</td>
<td></td>
<td>When there's no work to do at WAC Inc</td>
</tr>
<tr>
<td></td>
<td>Lots of clothes in my favorite colors, blue, red and black</td>
<td></td>
<td>When I go shopping staff don't let me buy some things I want</td>
</tr>
<tr>
<td></td>
<td>Getting my nails polished in many colors and many layers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Living with my new friend, Teddy, the Yorkshire</td>
<td>Sleeping on my bed at night</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Snacks from my plate</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>In my lap when I watch TV</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Favorite people doing activities with her, especially John Dandy</td>
<td></td>
<td>Julie is less steady on her feet and falling more than she used to</td>
</tr>
<tr>
<td></td>
<td>Keeping Julie from falling</td>
<td></td>
<td>If you don't make a plan with her before shopping, she will want to buy more than she has money for</td>
</tr>
<tr>
<td></td>
<td>Reminders to use her walker</td>
<td></td>
<td>Julie may get very upset which can alter her blood sugar</td>
</tr>
<tr>
<td></td>
<td>Blood sugar kept level</td>
<td></td>
<td>Julie gives Teddy food off her plate which means staff can't accurately track her nutrition</td>
</tr>
<tr>
<td></td>
<td>Staff know Julie's signs of low and high blood sugar</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Given the medication that someone is taking

- What makes sense, is working, the up side, right now
- What doesn't make sense, is not working, the downside, right now

Your guess’ about the Person’s perspective

Your /Staff’s perspective

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Working/Not Working

For the Person -
• Results in greater clarity about what needs to stay the same and what needs to change in each person’s life
• Helps in determining goals/outcomes that help the person move toward a desired life

For the Organization -
• Teaches critical thinking
• Promotes better problem solving
• Leads to clarity about what needs to change and what needs to stay the same
• Supports a learning culture

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<table>
<thead>
<tr>
<th>Date</th>
<th>What did the person do? (What, where, when, how long, etc.)</th>
<th>Who was there? (Names of staff, friends, others, etc.)</th>
<th>What did you learn about what worked well? What did the person like about the activity? What needs to stay the same?</th>
<th>What did you learn about what didn’t work well? What did the person not like about the activity? What needs to be different?</th>
</tr>
</thead>
<tbody>
<tr>
<td>3/1</td>
<td>Hillsboro Aquatic Center for hot tubing (2 hours)</td>
<td>Charlie, Aaron, John, Trina and two strangers</td>
<td>He liked the long warm soak part. The hot tub temperature is set at 105 degrees, which is not too hot for Charlie. Charlie especially liked floating on his back with Aaron's support. We saw lots of smiles and a very relaxed Charlie.</td>
<td>Charlie did not like getting rain on his face when we were getting in the van. We need to take an umbrella when we go out on rainy days. The lift was not available when we arrived at the center. Call ahead next time. (503-648-9884)</td>
</tr>
<tr>
<td>3/4</td>
<td>Fishing at Hide-a-way resort (2.5 hours)</td>
<td>Charlie and Aaron</td>
<td>He liked catching the trout and got so excited he didn't want to leave. Charlie liked the hot cocoa &amp; cookies we shared.</td>
<td>We need to figure out a way for Charlie to hold his pole more on his own.</td>
</tr>
<tr>
<td>3/5</td>
<td>Neighborhood walk (30 min)</td>
<td>Charlie, Trina, Aaron</td>
<td>Charlie likes to greet the dog at the corner of 5th and Jense. We stop for about 10 minutes each time we walk.</td>
<td>Today we tried to go a different way. Charlie was not happy which we turned around and went down 5th St. Take a dog biscuit next time!</td>
</tr>
<tr>
<td>3/5</td>
<td>Reading with his new glasses (1 hour)</td>
<td>Charlie and Mrs. Endicott</td>
<td>Mrs. Endicott and Charlie read a fishing magazine &quot;Northwest Fishing&quot;. He loved having Mrs. E to himself for a little while! They had lunch together also. The glasses really help Charlie see the pictures.</td>
<td>He was not interested in the car magazine she brought. Not sure if it was because he was hungry or because he wasn’t interested in cars.</td>
</tr>
<tr>
<td>3/6</td>
<td>Shopping in downtown with a walk (1.5 hours)</td>
<td>Charlie, Don, and Judy</td>
<td>Charlie got very excited and yelled out a few times when we were looking at video games, at Electronic Salon. A woman in the book store took special interest in Charlie and helped us find books on fishing (at Dohnn)</td>
<td>Construction at the mall downtown (Pioneer Square) made our time not as fun. There were lots of detours on narrow paths and the smell of some fumes made Charlie's eyes water and caused some discomfort.</td>
</tr>
</tbody>
</table>
Mindful Learning: Learning Log

For the Person -
• Because people are recording what is working and not working in support –
  – More of what is working and
  – Less of what is not working will occur

For the Organization -
• Those doing the work feel listened to
• Learning done by those doing the work is recorded
• Provides a vehicle for learning to be synthesized and recorded
• Helps with problem solving/hypothesis testing
• Creates good paper
• Reinforces a learning culture and teaches critical thinking

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4 + 1 Questions

• Using the “4 questions” to focus on learning and acting on that learning –
  – What have we tried?
  – What have we learned?
  – What are we pleased about?
  – What are we concerned about?

• And then
  – What should we try/do based on what we have learned?
4 + 1 Questions

For the Person -

• Provides a record of those things that have been tried and their efficacy
• Those who support are less likely to continue to do those things that are not working in support
• Figuring out better ways to support people are likely to happen faster

For the Organization -

• Everyone has a voice and feels listened to
• Collective learning/knowledge is gathered efficiently
• More effective use of meeting time
• Facilitates effective problem solving

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Sally’s One Page Profile

What People Like and Admire about Sally

• She is tenacious
• She’s good at helping others learn what needs to be done, what the routines and expectations are
• She is kind and helpful
• She is funny and a good at joking around

What is Important to Sally

• Having things done the way they are “supposed” to be done (e.g., laundry protocol)
• Her music and her MP-3 player
• Having a routine that she follows
• Having time with kids or other ways she can be “helpful”

Supports Sally Needs to be Content, Healthy and Safe

• Sally eats very slowly; and needs her foods cut up before her plate is put in front of her
• Give her time to process requests; it takes a while for Sally to make up her mind. She does not like to be rushed.
• Due to her seizures, Sally needs to wear her helmet whenever she is walking
• Do not touch or move Sally’s belongings without her permission
• Routines and rules matter to Sally: there are specific protocols for supporting Sally (seizure, bathing, laundry, helmet, bag, family contact); staff must be familiar with each of them and follow them
• Find time for joking a teasing with Sally

Supports, continued

• Remind Sally to “walk slowly” so she doesn’t fall
• Right now, Sally’s food plan does not include sugar or caffeine; help her choose foods that meet this requirement
Chad's One Page Profile

WHAT IS MOST IMPORTANT TO CHAD

~ Not being asked if he feels sick
~ Not taking about bad things or feelings
~ Having his CD player and earphones all the time
~ Playing skateboarding and motorcycle mania on the playstation
~ Not being told what to do "I hate that"
~ Being seen and treated as an adult "Don't talk to me like I'm dumb"
~ Being outdoors (bad weather can be depressing)
~ Being done with paperwork at school
~ Getting a cell phone SOON!
~ That people don't touch his stuff
~ Keeping his things clean and organized (either with him or in his room)
~ Not talking about his IEP in front of other people
~ Riding his motorcycle, working physically hard, staying fit
~ Getting a job as a landscaper
~ Staying close to Mom and Dad, but living with Mom on the Coast
~ That mom and Dad get along

WHAT YOU NEED TO KNOW AND DO TO SUPPORT CHAD

~ Give short instructions/time to process
~ Describe things not by name, but by appearance, smell, texture etc
~ Model new tasks, then let him try
~ Asking for his help always works better than telling him what to do
~ Help Chad voice choices, especially "no"
~ On the job, he will stop working if others stop. His schedule should be written very explicitly.
~ He has great safety skills and should be allowed to bike/bus anywhere.
~ Remind Chad to look at people when he talks, and to use a loud voice
~ Don't bring up family issues - let him do it. He's very sensitive to his folks divorce and how they interact with each other.
~ Chad is skilled and competent running machinery and equipment and is offended when people don't let him due to his disability. "I have experience! I know what I am doing"

WHAT OTHERS LIKE AND ADMIRE ABOUT CHAD

~ Polite * Sensitive
~ Cheerful * Strong
~ Hardworking * Athletic * Funny
~ Determined * Competitive * Competent
~ Good Humored
But there has to be more than training

- Training introduces skills
- Without more than training the impact diminishes over time
- Skills are learned but not regularly applied and then largely forgotten
- The remnants of the skills are in the forms that have become empty rituals
There has to be an effort that takes the skills from training to habit
Those who take skills from training to habit are coaches, person centered thinking coaches
Coaches help the skills become habits

• Support the pervasive and routine use of the skills
  – In day to day work
  – In problem solving

• Use the skills to develop “living descriptions” of how people want to live through partnerships with –
  – Those who use the services
  – Family members
  – Those closest to the person

• Make and celebrate level 1 changes
• Create optimistic discontent
Leaders listen and act on what they hear

• Structured opportunities to listen to coaches for –
  – What needs to be celebrated, supported, and/or shared
  – What needs to change
Leaders develop a change strategy

• **Approach** –
  – What methods/strategies will you use? Is it repeatable?
  – What is the sequence of activity?

• **Deployment** -
  – Which departments will be included? Which areas, offices or locations? Which service sector?

• **Communication** -
  – Who will need to know, and how will they be informed?
  – How will you make sure it is uniform?

• **Learning/Evaluation** –
  – How will you determine that your approach is effective?
  – How will you know it is working? What is your strategy for learning from your approach?
  – What measures will you use?
Leaders use “quality management” techniques

• Measure progress
• Aggressive efforts to reinforce person centered practices and improve organizational efficiency –
  – Review of processes and structures
  – Ruthless review of all paper requirements
• Integrate learning –
  – Change policies, structures, practices
From individual to system change

Level 1 changes
Change what we can change
Should create more opportunities for

Level 2 changes
Change what we can change
Should create more opportunities for

Level 3 changes
Change what we can change

Team level
Implementing Person Centred Practices

Organisational level

System level

Working
Not Working

Working
Not Working

Working
Not Working
It Goes Beyond Person Centered Planning...
What changes do we see in each level?

- Changes in one person’s life
- Changes in language
- Changes in our tools and documents
- Changes in system structure and external relationships
- Changes in our processes and our structure
Transactional vs. Transformative*

- **Transactional Dynamics** – the everyday interactions and exchanges that create the working climate; changes in these interactions can change the climate of the workplace; structure, roles, reporting, tasks, management practice, supervisory activities etc.

- **Transformative Change** – change within an organization that creates a shift in values or culture; generally requires “entirely new behavior sets on the part of organization members”;

W. Warner Burke in "Diagnosis for Organizational Change" p. 71-72,  A. Howard et al.

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Transformative Change

- Culture Change permeates the full organization:
  - Leadership
  - Employees
  - Service Delivery/Programs
  - Business Departments – Finance, Information Technology, HR
  - Mission/Vision/Values and Strategy
  - Relationships with external organizations and partners

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Transformative Change

• Focus on becoming a learning organization – **continuous quality improvement**
  ▶ Dedicated to learning from all engagements, alleviating blame culture, and building strong partnerships internally and externally

• Full organization is focused on how to move beyond simply meeting standards
  ▶ recognizing compliance as the floor, not the ceiling, of high quality service/performance.
What have states changed?

- Referral process
- Outcome Development process and training
- Process to develop and deploy all new policies
- Crisis services
- The Role of Licensing agencies
- ISP documents
- Waiver requirements
- The role and approach of Behavior Analysts
- Risk Assessment process
What have private agencies changed?

- Performance review procedures and policy
- Strategic planning processes
- Discussions with Families about transition
- Transportation policy
- Hiring/Interviewing
- Referral
- Assessment methods, documents
- Outcome/goal development methods
- Daily Documentation (reduced paperwork)
- Signs, language used in formal communication
- Orientation of new staff
How did they make the changes?

The Structure of the Change Efforts:

• Training in person centered thinking skills for all staff – leaders, administrative staff, system managers, providers and support/service coordinators at the same time

• Frequent, structured, planned sessions designed to develop skills and support Person Centered Thinking coaches so that the understanding spreads throughout all agencies.
How did they make the changes? (2)

• Intentional learning sessions for leadership to listen to coaches and both to learn from each other; used person centered tools to facilitate a parallel process

• Build local capacity and capability to create sustainability
  – Person centered thinking trainers
  – Teach leadership/quality management skills and how to apply them

• Purposeful approach to build stronger partnerships between all of the key stakeholders
From the system we need

- Vision, mission and values that are routinely used
- Sustained efforts in building partnerships
- Supporting advocates (self advocates and families) to learn how to write up what they want, how to look for what they want, and how to get it (within the resources available)
- Offering training and technical assistance to those who provide the services to deliver what people are asking for
From the system (2)

• Ongoing learning about what works and doesn’t work at all levels

• Systems thinking, how the parts work together, how to leverage change, how to break down silos

• Analysis that says
  – What can be done at scale
  – What can become expected practice

• Actions that move the system toward the vision
To help people move to better lives

• We need –
  – Descriptions of what a better life looks like
  – A process where the person (with their advocate) looks for services that match the description
  – The available public resources can be used to buy the best match
From advocates we need

• Persistent impatience (don’t give up)
• Positive pressure for change – and providing “protection” for those who lead change
• Getting the training and support needed to describe what you want and to evaluate what is offered
• Insisting on both self direction and partnership
IT'S ALL ABOUT ME

ELIZABETH KAY

A Few Things That Are Important TO Me...
(Please see pages 6-10 for more information)
- My independence
- A thriving social life
- Being organized and prepared
- School – Graduation in May 2011!
- Taking good care of myself
- Routines
- Planning for the future – including a job, an apartment, and a boyfriend
- Everything Michael Jackson
- Diet Coke
- Singing at church
- Fun with friends & family
- Writing in my journals
- Avoiding conflict
- Fashion
- Close relationships with Family & Friends

What we love about Elizabeth!
(see pages 4-5 for more info)
- She’s a determined self-advocate – ask her about her rally speeches
- A gutsy gal
- Talk about organized!
- A true blue friend
- She lights up a room!
- She’s a Fashionista

...And A Few Things That Are Important FOR Me:
(Please see pages 11-13 for more information)
- CPap machine, plenty of sleep (may include naps)
- Seizure medications
- Healthy diet and exercise
- Writing in my journals
- Conflict free environments & relationships
- Avoiding a “fireball”

Here’s How You Can Support Me:
(Please see pages 12-14 for more information)
- Help me with time, money, cooking, shopping & some cleaning
- Help me find a job and job training
- Assist me to fix my hair & pick out cute outfits
- Help me make healthy food choices and to exercise
- Understand if I’m upset, I’m probably tired.
- Talk to me nicely & quietly. No bad words.
- When people around me are angry or there is conflict, help me get away
- Help me understand what’s going on, what to expect
From agencies

• A sustained commitment to
  – Support those who provide direct support to have the skills to truly listen
  – Look at what is working and not working for each person
  – Act on what is learned

• A willingness to be change targets as well as change agents
From professionals

• Describing and advocating for supportive and healing environments
  — Looking at clinical efforts in the context of how people live and are supported

• To integrate best practice in clinical interventions with best practice in person centered systems work
From the universities we need

• Research and analysis that
  – Identifies which efforts
    • Move us toward the desired outcomes and
    • Can be done at scale
  – Supports these “promising practices” to go to scale and become “evidence based practice”
We are in this together

Our response to increasing demand and fewer public resources will determine whether people with disabilities have lives

— Of increasing isolation, or

— Increasing inclusion
For more information on:

Going to Scale:
From Person Centered Planning
to
A Person Centered System

Contact: Support Development Associates

Michael Smull
Email: michael@sdaus.com

Mary Lou Bourne
Email: marylou@sdaus.com

Downloads available –
Best Practice, Expected Practice, and Scale at
http://www.nasddds.org/pdf/BestPractice&ExpectedPractice.pdf

Becoming a Person Centered System – Brief Overview